

1. Adapting a Family-Focused Diabetes Prevention Program for a Federally Qualified Health Center: A Qualitative Report

2. Family-focused diabetes prevention

3. Patrick Rivers, MPP*; Melanie Hingle, PhD, MPH, RDN**; Griselda Ruiz-Braun*; Robert Blew, MS**; Joy Mockbee, MD***; David Marrero, PhD*

4. *University of Arizona Department of Health Promotion Sciences; **University of Arizona Department of Nutritional Sciences and Collaboratory for Metabolic Disease Prevention and Treatment; ***El Rio Community Health Center

5. 655 N. Alvernon Way, Suite 228
Tucson, AZ 85711
520-621-0088
520-626-1986

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Abstract

Purpose: The purpose of the study was to explore the needs of high-risk Latinx/Hispanic women with a history of gestational diabetes who were patients at a Federally Qualified Health Center (FQHC) in anticipation of a future family-based program.

Methods: Six focus group studies were conducted in partnership with El Rio Community Health Center, an FQHC in Tucson, AZ. Thirty-nine women participated, each identified as Latinx/Hispanic, self-reported a history of gestational diabetes or prediabetes and had at least one child aged 8-13. Three investigators independently reviewed transcripts from the focus groups to identify themes that reflected thematic saturation from participants' responses. Data coding and results were discussed as a group and any differences were collectively adjudicated.

Results: Each participant had a family member with diabetes and worried about their and their immediate family members' risk for developing the disease. The possible benefits of participating in a life-style prevention program were universally recognized, but multiple barriers to participation were described, including scheduling conflicts, access to childcare, transportation, and the need to involve additional family members to reinforce program objectives.

Conclusions: There is a strong willingness to participate in a diabetes prevention program among respondents, but to be successful, interventions must be tailored to specific needs and challenges. Trying to apply existing prevention curricula with low-income Latinx/Hispanic populations may not be successful without adaptations.

Introduction

In the late 1990s, three seminal studies demonstrated that diabetes prevention was possible for persons with increased risk factors, most notably, the presence of impaired glucose tolerance. The Da Qing and Finnish Diabetes prevention studies, and the U.S.-based Diabetes Prevention Program (DPP), each conducted with different racial and ethnic populations, demonstrated conclusively that lifestyle interventions that targeted modest weight reduction (5-7% of total body weight) and increased physical activity could prevent or significantly delay the onset of type 2 diabetes.¹⁻³ Given the growing epidemic of diabetes worldwide, these findings prompted efforts to replicate and disseminate these diabetes prevention interventions in order to broadly reach those at risk and impact public health at a larger scale.⁴⁻⁶

In the U.S., these initial efforts largely replicated the DPP curriculum, an intensive 16-week lifestyle modification program developed as part of the larger DPP clinical trial, which tested the effects of the intervention compared to a metformin group and a placebo control.⁴ Although the lifestyle program fared best in the clinical trial (reducing the incidence by 58 percent, and metformin by 31 percent as compared with placebo), scalability of the program was a concern, with extensive incentives and resources being used to support trial adherence.⁴ Indeed, without these incentives, many community-based intervention programs have since faced difficulties in both engaging and retaining participants.⁷ These difficulties have been compounded by the growing need to develop programs that are responsive to cultural differences of high-risk populations. In this context, the structure and content of the DPP-based

curriculum does not always address potential barriers to participation that are experienced by many high-risk cohorts.

To address these issues in both design and delivery of a community-based diabetes prevention program for women at high risk of diabetes, the authors conducted a series of focus groups to explore the needs of high-risk Latino/Hispanic women with a history of gestational diabetes who were patients at a Federally Qualified Health Center (FQHC) in anticipation of a future family-based program.⁸

Methods

Research Design: Given the challenges researchers have faced in translating the DPP curriculum for community interventions with underserved populations, this study was conducted to better understand the specific barriers and facilitators that exist for the unique population of southern Arizona. A qualitative research study design was chosen as it better captures information directly from patients not conveyed in quantitative data including information about beliefs, values, feelings, and motivations that underlie behaviors, and variables important for future studies and interventions.⁹ Focus groups were chosen as the preferred methodology to get the views and opinions of as many individuals as possible.

Sample: Potential participants were identified from the patient population at El Rio Community Health Center, a Federally Qualified Health Center serving more than 100,000 uninsured and underinsured individuals in Southern Arizona. A majority of the FQHC's patients identify as Latinx or Hispanic. Women with a history of gestational diabetes and who currently had at least one child between the ages of 8 and 13 years were identified through a search of the FQHC's Electronic Medical Record. The study team employed FQHC physicians to conduct a direct

solicitation to their patients who met this inclusion criteria. Interested women were invited to complete the consent process, and were scheduled to attend one of six potential focus group dates and times. A script was developed by the investigators to guide discussions, and study approval was obtained from the University of Arizona Institutional Review Board (approval number 1810003347).

Focus Group Methodology: Six focus group studies were conducted with FQHC patients between January 25 and February 16, 2019, with between six and nine individuals participating in each session. A total of Thirty-nine women participated in the focus groups, which were conducted at the administrative headquarters of the FQHC or a meeting room at one of the FQHC clinics. Groups were led by one principal, experienced facilitator (GRB), who comes from this community and has extensive experience working with the study population. The facilitator was provided with logistical support from one to two secondary facilitators and FQHC staff. Session durations ranged from 60 to 90 minutes and were conducted at varying times of the day across multiple days of the week, including the weekend, to include participants with variable schedules. Following each session, the facilitator debriefed with the study Principal Investigator to provide impressions of the group process and affective reactions of individual participants that were not available from either the audio recordings or the transcripts.

Focus group questions were designed to elicit participants' perceived risk of developing diabetes, ability to reduce risk, and their reactions to proposed elements of a future diabetes prevention program offered by the FQHC. Focus groups were audio recorded and transcribed by a trained transcriber employed by the University of Arizona. Transcripts were used to determine if thematic saturation had been achieved, which was reached when there was

enough information to replicate the focus groups, when no additional new information was found, and further coding was not necessary.

Three investigators, trained in qualitative data analysis (PR, DM, GRB), independently reviewed the transcripts to identify potential themes. They then met as a group to compare their reviews and agreed upon themes that reflected relative thematic saturation of responses. All coding was discussed by the three reviewers in a group session where differences in coding were adjudicated. It was determined that thematic saturation was achieved after approximately 11 participants.¹⁰ Transcripts and the coding guide were sent to an independent investigator who was not a member of the coding or original analysis team. This individual then scored the transcripts to determine if the coding scheme resulted in assessments similar to those by the research team. This effort was reviewed by one of the study investigators (DM), with a high correlation between scorers (>95%). Perceptions and recommendations of the participants were summarized and analyzed using the scoring guide categories.¹¹

Results

Awareness of Diabetes:At the outset of each group, the moderator began by asking participants if anyone in their family, or any friends or neighbors had diabetes. Almost all of the participants (91%) reported at least one first-degree relative with diabetes and all of the participants (100%) personally knew someone who has the disease.

“I had seven children and they all have diabetes, my husband has diabetes, everyone has it except for one of my daughters.”

Participant awareness of the prevalence of diabetes in their families and in their communities was also reflected in their responses when asked if they personally worry about diabetes. The

majority of respondents (>95%) reported that they were concerned. There was also confusion by some respondents about whether they currently had diabetes due to their diagnosis of gestational diabetes during a pregnancy.

“I do worry about it as well. I think I was a little frustrated, scared and annoyed at the same time while I was pregnant and going through [gestational diabetes].”

Participants were asked if they thought there was anything that they or a family member might do to prevent diabetes. Prior research with some racial and ethnic minority populations in the U.S. suggests that beliefs regarding the inevitability of diabetes might be prevalent.¹² While some individuals in the focus groups expressed a belief about inevitability, it was fewer than 5%.

Strategies for Diabetes Prevention: Over 85% of participants stated that there were things that they could do to prevent diabetes, with primary emphasis on diet behaviors and reducing weight.

The most frequently mentioned strategies (in order of prevalence) were:

1) Improving diet (>70%)

“I think ameliorating the diet is the most important factor”, “It’s really about retraining your mind about your relationship with food”;

2) Reducing weight (52%)

“The doctor tells me that since my Dad is diabetic, I have to lose fifty pounds so that I’m not at risk of developing Diabetes.”;

3) Eating out less/more at home (50%)

“I would say less carbs, like more healthy food to less fast food, more home cooked meals versus going out a few times a week to limit going out to eat”;

4) Getting frequent medical checkups (16%)

“Go get check-ups because it’s a silent disease. You usually don’t know you are at risk until you get it”; and

5) Eating less sugar (5%)

Barriers to Engaging in a hypothetical Diabetes Prevention Intervention: The group facilitator briefly described the potential for a lifestyle intervention and provided a brief description of how such programs are structured, with an emphasis on weight regulation as a key element. Participants were asked to reflect on how easy or difficult it would be for them to join a prevention program designed to support them in making lifestyle changes that would help them lose weight. None of the respondents stated that it would be hard to do, and many reinforced the importance of such efforts. At the same time, participants consistently noted several factors that might make it difficult for them. A vast majority (>90%) stated that the complexity of their schedules was the most important barrier to participation. This concept was further clarified as scheduling conflicts associated with work and other activities, and those relating to their child(ren) and school activities and schedules. The next most frequently noted difficulty was the need for childcare at the program so that participants could focus on learning, closely followed by issues with transportation and getting to a location where the intervention would be held. Some participants (10%) noted that they would have to view the program as “worthwhile” or that it would have to “keep my interest” in order to participate.

When asked what would make it easier for participants to attend and engage in a lifestyle intervention program, participants continued to speak about potential barriers. A small

percentage (16%) suggested that offering cooking classes to guide healthy meal preparation would stimulate their participation.

"It would be good to actually cook something because your cooking skills could be, you know limited and anyone can do this, you know? Even the kids can help and that would be nice."

Structure of Potential Intervention: Participants were also asked how they would feel about participating in a program with others who they may not know but who share risk of diabetes. There was wide acceptance for the inclusion of others, regardless of whether or not they were known (>90%). The rationales offered were varied, but mostly centered on the ability to learn from others who share similar circumstances (81%) and get "tips" from others who might have different ideas about how to change family behavior (61%)

"It does interest me a lot to join one of those groups because I don't think I know what iabetes is, I just know what I hear from others. In reality, I don't know how it all starts, what symptoms to look out for", "I think getting involved into one of these programs will help motivate others to work on these factors as well, I would like to be a part of a support system. Especially because I knew reaching my goal was not easy."

Since all of the focus group participants were women and a future intervention is proposed for women with a history of gestational diabetes, participants were asked if they preferred a mixed-gender or single-gender program. There were differences in the responses. The majority (71%) felt that mixed groups would be beneficial. The primary rationales for this included their desire to improve their partners' understanding of risk and what has to be done to increase acceptance of dietary changes, to get partners on board to help reinforce lessons with children, and to make the entire family aware of risk factors and the seriousness of diabetes:

“Once the whole family is involved with the subject, in this case diabetes, the family benefits from it and it’s nice they all help each other out. We can all be supportive towards each other.”

Of the 29% of respondents that preferred a female-only program, the main rationale was their belief that there were issues that were more likely to be discussed if partners were not present. It was mentioned that with partners (in this case, specifically male partners) attending, some issues were less likely to be raised by women:

“I would not like men involved. I personally would like a female focus group. I would feel more comfortable”, “I just feel personally that it would be easier to speak openly and not worry about it.”

Make-up of Intervention Groups: The issue of who should be included in an intervention program was further explored by asking participants whether other family members should be invited to attend. There was universal (100%) positive affirmation for including other family members, especially children. The primary rationales for this were the need to reinforce healthy eating (72%); increase family understanding of how to reduce risk (66%); the need to emphasize the seriousness of disease (>66%); and the belief that family participation will help to reinforce lessons (38%).

“It would be nice if there was a group where our family members could also participate, parents along with their kids because I think there are groups like these for us but not really for a family. I have a son that is nine years old and thank God he is healthy but I am interested in learning more about it because my mother has diabetes. Therefore, there is a risk. I can take care of myself but if we took these classes together as a family, we would do a lot better as a whole.”

The idea of including children in a prevention program was further explored. Participants were explicitly asked if they felt that their children should participate. There was a universal (100%) positive response for including children. There were several rationales provided for this. The primary reasons were that it would reinforce the objectives of session lessons, making it easier to implement at home (> 40%); children might understand issues better when participating with others who share similar issues: (30%); participating in a program might motivate children to help around the house (cooking) (20%); having their children participate can help motivate adults to exercise (20%); and, including their children would provide social support to make lifestyle changes (18%).

“There are many heavy kids nowadays who have these issues. So, it’s good that as kids they learn what is good for their own health”, “It is very important that [children] start learning about the care of diabetes at a young age. It is important for their future and for when they have a family of their own. It is important they have a foundation of how to have a healthy lifestyle.”

The participants were also asked if children were formally included in an intervention program, whether they should be in a separate session held at the same time as the adult program or be folded into a shared program with their parents. This question generated considerable discussion about the pros and cons of the different options. The main preferences were for a shared program (50%) with the rationale that it would keep the kids more focused and would support adoption of changes at home, particularly dietary modifications:

“[Children] would also be able to help around the house, they would help with the diet, with exercises, they could motivate us to go for walks and not just to be on our phones or tablets.”

There was also desire for separate programs (43%) with the rationale that children will learn better in peer settings and are more likely to accept information from peers versus parents:

“I think that kids tend to learn better when they are around other kids and not when adults are around”, “I think it would also be a good idea to teach them information that is on their level, it should be kid-friendly”; with only a small percentage (7%) suggesting they would prefer a format where for part of a program session children are separated and part of the time they were combined with their parents.

Logistics of Intervention: Several questions were then asked about how an intervention program should be formatted and organized. The first question was about where such a program should be held. Responses were largely influenced by where the respondents lived and their familiarity with the FQHC facilities where they receive care. The main preference (>70%) was the FQHC itself. The remaining responses (11%) suggested “convenient community locations,” such as libraries and community centers.

When asked how often sessions should be held, there was almost an even divide between weekly (46%) and every other week (43%). Thirty-four percent also suggested that there should be recurrent sessions, i.e., where the same session is held twice in one week to enable participants to do “make up” should they miss a session.

When participants were asked when sessions should be held, there was considerable variability in responses, mostly dictated by scheduling issues. The majority of respondents preferred evenings over daytime (>70%). It was suggested that this would enable easier scheduling and inclusion of children. In addition, weekdays as opposed to weekends were

preferred (>60%). The main rationale was to keep weekends free for family activities and allow for youth sports scheduling.

Participants were also asked how long they felt each session of a program should be. There was almost universal agreement for “an hour to an hour and a half” with 82% preferring 60 minutes, and 66% preferring 90 minutes – with a significant number expressing both would be acceptable. These responses were qualified by what type of activities were being conducted, with the 90-minute timespan being usually justified by including cooking lessons.

Several questions were asked about participants receptivity to different activities during program sessions. They were asked how they would feel if there was some group and some individual activities. There was near universal acceptance of mixed activities (93%), with 7% stating that it would depend on the activity.

Because low literacy has been observed in this FQHC patient population and the DPP format curriculum relies on the extensive use of worksheets, receptivity to written tasks during program sessions was explored. The majority of respondents (65%) stated no objections. Thirty-two percent stated that it would depend on the task, but declined to elaborate on what tasks would or would not be acceptable.

Participants were also asked about the acceptability of “homework” between the sessions, e.g., writing down what they ate each day in a log book. The majority of respondents (77%) felt this was acceptable and would help them control what they ate. There were respondents (23%) who were not enthusiastic about this idea and usually stated that it would depend on the task.

To follow-up on the discussion of tracking food intake, participants were asked if they thought using an app on their phone to track what you ate would be as useful or better than pen and paper. There was mixed response to this question, where 56% felt that pen and paper would be easier for them and 44% liked the idea of a phone app. Several respondents (20%) noted that their cell phones did not have sufficient memory to accommodate an app. None of the participants were currently using dietary apps.

Respondents were also asked how they would feel if there was physical activity conducted during the sessions. The vast majority of respondents (90%) felt that having physical activity was a good idea, with only 10% not in favor of including physical activity in the program sessions.

Barriers to Proposed Intervention Participation: Finally, the basic model for a program that was discussed during the focus group session was described and respondents were asked what are some potential barriers that might arise that would make it hard for them to participate in such a program. There were several barriers mentioned, but the vast majority mentioned:

- 1) Scheduling conflicts/difficulties – both personal and child activities (>90%):

“It would be hard to coordinate all of my family members schedule”, “It is hard to get all of us together at the same time”;

- 2) the need for childcare (68%):

“Childcare will be a problem for me because I have a baby and an eight-year-old, so it would be hard to pay attention to the session while I’m nursing or changing a diaper”; and

- 3) the need for transportation to attend sessions (56%):

“Transporting from place to place is also my concern. My husband works in the evenings and I work in the mornings so it’s a hassle because he has to take me and then pick me up. There is no means of transportation I can use once he goes to work.”

Discussion

The increasing prevalence of type 2 diabetes firmly establishes the disease as a major public health issue. In the Latinx/Hispanic populations – who experience disproportionate rates of diabetes and often live in communities where diabetes is prevalent – it is of particular concern. This was illustrated in the focus groups by the near universality of individuals with first-degree relatives suffering from diabetes, and the high degree of worry felt by the participants over their own health. It was clearly established that the participants were aware of their risk for developing diabetes and understood the importance of participating in some type of prevention program. It was also apparent that any diabetes prevention intervention must be responsive to the specific vulnerabilities and challenges of these individuals. This is a finding that has been frequently observed in other studies.¹³⁻¹⁵

The findings clearly illuminate that a successful intervention for a predominantly low-income Latinx/Hispanic population should consider a range of cultural and socioecological factors. Several potential barriers were identified that might inhibit engagement and continued participation in intervention programs. These include concerns about changing diet habits in the home, and difficulties in scheduling, childcare, and transportation. Scheduling was the most frequent concern due to the necessity of many of the participants to be involved in a combination of family support and work, which often makes participating in what may be viewed as a “non-essential” activity difficult. The issue of scheduling is compounded by the frequently observed

issue of transportation limitations, which is often the result of there being only one car available to a family and unreliability and/or time-consuming nature of public transportation in the region. In addition, many of the mothers interviewed had multiple children across a broad age range, which posed additional scheduling challenges. Finally, the women interviewed had primary responsibility for food preparation. This reality added to the concern that getting their partners and children to accept dietary changes was a potential barrier, and may have contributed to why participants expressed very specific preferences for how intervention groups should be organized and conducted (i.e., mixed-gender and inclusive of families). Having multiple families present during intervention activities was viewed as an important way for participants to learn from others who shared similar challenges and who might offer ideas on how best to cope and to reinforce the importance of program content within the family. There was also a strong opinion that partners and older children should be included into the programs. This was argued to be a beneficial way to teach their families about the severity of diabetes, to educate partners about what changes in the family environment would be needed to reduce diabetes risk, and to engage their children in the lifestyle changes that would be implemented in the home.

Consistent with concerns about scheduling, participants advocated for program sessions to be held at times that were convenient for both their children's school and extracurricular activities schedules and their partner's or their own work schedules. In this context, weekdays, especially in the evenings, were identified as the best time to hold sessions, either every week or every other week. Sessions should be at least an hour long and up to an hour and a half if there were activities planned like exercise or cooking demonstrations. If "homework" was assigned –

such as tracking what participants ate – it should either be done with pen and paper or a combination of pen and paper and technology like a smartphone app.

Implications

This research highlights some of the possible challenges faced by Latinx/Hispanic female FQHC patients with high risk for developing type 2 diabetes, and their children, who are asked to consider participation in a diabetes prevention intervention. The standard DPP curriculum, while effective in achieving desired levels of weight reduction, has been shown to have low effectiveness with racial and ethnic minorities and individuals from lower income households, leading to high rates of drop-out.¹¹⁻¹³ This could be in part due to how these interventions are organized, e.g., at times and locations convenient for program leaders, but not for the participants. This data illuminate the importance of assessing the potential barriers and facilitators for program participation before attempting to implement a DPP-like program at an FQHC. These findings are important for most any urban area in the southwest or other cities across the country with high representation of racial and ethnic minorities, particularly Latinx or Hispanic persons.

The responses from these focus groups demonstrate a strong willingness to participate in an intervention of this type, and an understanding of its importance; but any successful intervention must be specifically tailored to the needs of this group. A primary goal of cultural tailoring is to increase access and quality of care for vulnerable groups. In this context, it remains important to document reasons for consent refusal, withdrawal, dropout, and missed sessions. When tailoring of prevention programs is done, efforts should be taken to measure effectiveness by linking tailoring strategies to either quantitative or qualitative outcomes. In this regard, it

continues to be important to obtain the feedback from potential participants regarding the acceptability and feasibility of intervention components and link them to intervention results.

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